

Testimony to the House Public Health Subcommittee  
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*The increase in autism prevalence is systemic across the entire United States and should be an urgent public health concern. The majority of the increase is attributed to young children. The increasing prevalence time trend provides additional evidence that disease frequency is, and has been, increasing in the United States. The disease of autism now surpasses that of all types of cancer combined.*

- *Michigan Public Schools Autism Report School Years: 1992-2003*

It is my pleasure to be with you today to discuss a topic that is of great importance to the families of our state; the mandatory coverage by insurance companies of medical diagnosis and treatments related to Autism Spectrum Disorder (ASD).

As a person who has spent 33 years in public education, much of it in special education, I have rarely seen a public health issue that deserves more prompt attention.

Michigan literally has thousands of children, their families, and public schools carrying the sole financial responsibility for the diagnosis and treatment of ASD currently denied by insurance companies. Imagine for a moment that you have a toddler whom you suspect is not developing at the expected rate and you seek a medical diagnosis. You make certain the doctor is in your PPO or HMO; get all the pre-approvals and once the evaluation is done and you learn your child has ASD, Asperger's Syndrome, or pervasive developmental disorder, that because of this, you will have to pay thousands of dollars for the diagnostic evaluation and for any future treatments, such as speech or occupational therapy, necessary to treat the disorder. Or perhaps you are one of the fortunate parents whose insurance will cover either occupational or speech therapy related to ASD – which ever one you choose, but not both - though if the child were in an accident or had some other disability both therapies would be covered.

The parent's main alternative, in these situations, is to risk financial ruin and/or seek as much service as possible from their school district, which may not have the necessary expertise to properly diagnosis the child, the financial resources to provide therapy, nor the responsibility to provide medical treatment. Another alternative may be to diagnose the child with a disability, other than ASD, that is covered under the insurance or attribute treatment to a medical condition other than ASD. The bottom line is that appropriate diagnosis and treatments are being denied

to children by insurance companies based on the sole criteria that they have ASD or a related condition.

At a time when we have a great need for public/private partnerships, House Bills 4476 and 4183, now before this committee, are timely. Only through cooperation can the medical and educational communities work effectively with families to minimize the life-long effects of this disability. I believe these bills will help schools and the medical community to work more closely together to better meet the needs of students with ASD. Figure 1 provides a 30-year snapshot of the increase in incident rates and associated educational costs related to ASD within the public education system.

Figure 1.

### Autism Spectrum Disorder Headcount and Public Education Costs

	SPED Head Count	ASD Head Count	Teacher/Para Salaries	Consultant Salaries	Teacher/Para Benefits (8.5%)	Consultant Benefits (1.4%)	Total estimated SOM funding for ASD related salaries and benefits
1976-77	151580	0	0		0		
1977-78	155270	0	0		0		
1978-79	160522	0	0		0		
1979-80	159398	0	0		0		
1980-81	160187	0	0		0		
1981-82	158479	0	0		0		
1982-83	160639	304	0		0		
1983-84	162952	414	0		0		
1984-85	167057	557	\$4,423,742.00		0		
1985-86	167097	682	\$5,840,321.00		0		
1986-87	166314	747	\$5,537,750.00		\$3,578,049.00		
1987-88	166574	848	\$6,298,849.00		\$4,334,376.00		
1988-89	166618	942	\$7,215,752.00		\$5,111,530.00		
1989-90	168700	1060	\$8,994,843.00		\$5,820,418.00		
1990-91	172738	1208	\$10,412,617.00		\$5,487,400.00		
1991-92	175464	1342	\$11,863,756.00		\$6,750,084.00		
1992-93	180114	1543	\$13,248,579.00		\$7,919,446.00		
1993-94	184245	1760	\$14,745,790.00		\$11,180,558.00		
1994-95	188703	2024	\$16,237,392.00		\$14,433,632.00		
1995-96	194365	2308	\$18,762,299.00		\$16,462,909.00		
1996-97	199244	2648	\$20,216,431.00		\$18,783,873.00		
1997-98	205879	3083	\$22,455,254.00		\$17,779,785.00		
1998-99	213869	3737	\$23,952,128.00		\$18,623,473.00		
1999-00	219659	4261	\$28,424,637.00		\$20,863,404.00		
2000-01	227002	4930	\$32,989,507.00		\$22,920,377.00		
2001-02	232440	5686	\$36,102,317.00	\$2,132,280.00	\$24,626,988.00	\$31,984.00	
2002-03	238327	6545	\$36,677,166.00	\$2,559,552.00	\$27,383,728.00	\$38,393.00	
2003-04	245018	7525	\$45,733,155.00	\$2,305,623.00	\$30,014,569.00	\$34,584.00	
2004-05	248030	8650	\$48,131,479.00	\$2,792,833.00	\$32,583,718.00	\$41,892.00	
2005-06	250769	10133	\$52,241,031.00	\$3,896,602.00	\$35,620,952.00	\$58,449.00	
2006-07	249006	11366	\$57,318,898.00	\$4,823,656.00	\$37,139,346.00	\$72,355.00	<b><u>\$99,354,255.00</u></b>
2007-08		Est.13839					

Author: Dr. Scott M. Koenigsnecht, Superintendent, Montcalm Area ISD, Parent of Cooper, 2009  
Assumptions: Teacher/Para benefits and consultants were calculated by taking the total expenditures of benefits in MI and multiplying by the respective percentages known to comprise those categories.

**NOTE:**

- 155% (1.55) increase in total special education head count since 1982-83
- 3738% (37.78) increase in total ASD head count since 1982-83
- 2246% (22.46) increase in State dollars since 1984-85

Figure 1 does not account for equipment, supplies, materials, etc. It also does not include any statistics related to the use of federal funds.

Figure 1 illustrates that the incidence and related costs to diagnose, educate, and provide educational support to students with autism spectrum disorder has virtually exploded.

I don't want to paint a picture of total despair. In Monroe County, we have formed partnerships with parents, other ISD's, and state universities to improve diagnostic and educational strategies. Today, most students with ASD spend most of their day in general education. One of these initiatives, "START" is administered through Grand Valley State University and the Monroe County ISD is concluding its fourth year of this grant-funded program which is focused on addressing the behavioral and educational challenges presented by students with ASD through the use of universal supports that improve educational experiences for all. Still, the challenge facing Michigan in coping with ASD cannot be met without research, early diagnosis and effective treatment strategies.

**Conclusion:**

When I started my career in 1976 there was no diagnostic category that addressed autism. Students were diagnosed and placed within a variety of programs. One of the primary categories was that of emotional impairments. As a teacher of emotionally impaired children, I had early exposure to children with ASD. One of the first children with ASD I encountered was Johnny. An acting-out child who spoke so fast that people thought he was mumbling gibberish. Gradually, staff and Johnny learned how to communicate with one another. Johnny's fascination with automobiles was one of the first unique things we knew about him – he knew everything about everyone's car. It took us awhile, but by 10<sup>th</sup> grade, "John" was able to be placed in general education full-time. At the IEP John wanted to take a foreign language and his mother vehemently protested. Finally, I leaned over to her and asked why she felt so strongly against his taking the foreign language class. She blurted out, "Because I am afraid that

he will never speak English again and I won't be able to communicate with him." I looked at John and told him that he had to promise me that he would continue to speak English if he took the class. He promised.

John graduated from high school with over a 3.0 GPA. He also did extremely well in his foreign language classes. A few weeks ago, I ran into John in a local pharmacy. I said "Hello John" and he immediately said "Hello, Mr. Spencer." We shook hands and he asked me about the teachers he had at the ISD, commenting on their dedication to students. John has worked full-time at a restaurant for many years and lives independently.

It is significant to note that during John's early schooling the MCISD worked with the Institute for the Study of Mental Retardation and Related Disorders, which then existed at the University of Michigan. They saw John on a scheduled basis, consulted with staff on his programming, and ultimately the University of Michigan no longer followed him because of the progress he made. This early relationship between the educational and medical community was critical in this students' long-term success.

John's story is not unique but it is not as ordinary as it should, and I believe, will be some day. But for this to happen, we need to confront this disability with all our available resources, both, public and private. In so doing, we will acknowledge that children with ASD do, indeed, make academic, communication and social gains as a result of their therapeutic and educational programs. This is a fact that parents, educators, therapists, and doctors know very well.

I, along with the Michigan Association of School Administrators, urge your support of House Bills 4476 and 4183 to end the discrimination by insurance companies against children diagnosed with autism spectrum disorder and related conditions.

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Thank you.